

Primary care service framework: Gypsy & Traveller communities

19 May 2009

1. Preface

The focus of this primary care service framework (PCSF) is Romany Gypsy, Roma and Irish Traveller communities; however, the principles it contains may be applied to develop services (or consult local people on developing services) for other Traveller groups, which are listed below:

- Scottish Gypsy Travellers
- Welsh Gypsies
- Bargees
- Circus and Fairground/Showmen (show people traditionally refer to both genders as showmen)
- New Travellers

It is important to note that not all Gypsies and Travellers live a nomadic life; many are settled although they may choose to travel for part of the year. Although there are differences of opinion, some experts say there are seven groups of Gypsies & Travellers living in the UK¹:

The largest group in England, possibly comprising half of all Gypsies & Travellers, is Romany Gypsies. There are no firm national data on the numbers of Gypsies & Travellers living in the UK, mainly because the 2001 Census did not identify Gypsies and Travellers as an ethnic category. This may change in 2011, as a code for Gypsies & Travellers may be included. There are estimates, however, ranging from 120,000 to 300,000 people. The upper limit compares with 280,830 Bangladeshi people and 226,948 Chinese people.

In Leeds, the Race Equality Council – with the support of Leeds Gypsy and Traveller Exchange (GATE), local communities and using community enumerators - has identified at least 345 Gypsy & Traveller families representing 1,071 people².

¹ Romany Gypsies – who settled in the UK over 500 years ago, Roma – more recent arrivals from Eastern Europe, Welsh Gypsies (the Kale), Irish Travellers (who have been coming England for centuries, possibly millennia) Scottish Travellers, New Age Travellers, show-people (including circus performers and crew)

² Gypsies and Travellers Leeds Baseline Census 2004-2005" (. <http://www.gypsyromatravellerleeds.co.uk/information/academicStudies.html>)

It is important to recognise that each of these groups has its own histories, traditions and culture.

Under race relations legislation, Romany Gypsies and Irish Travellers are both defined as minority ethnic groups. This means that NHS bodies as public organisations must consider the needs and circumstances of these communities when meeting their general and specific duties under the Race Relations (Amendment) Act 2000.

Equality and human rights

Delivering good quality care means that PCTs should demonstrate competence in identifying and taking action on inequality, particularly for Gypsy and Traveller communities that do not find accessing NHS services always easy. PCTs are reminded that:

- “Healthcare organisations should enable all members of the population to access services equally and offer choice in access to services and treatment equitably” (Standards for Better Health, Core standard C7e)
- Undertaking Equality Impact Assessments (EqIAs) of services, policies and functions is a specific legal obligation on most public bodies. Using the evidence from EqIAs is central to effective commissioning and service provision. The drafting of EqIAs can be used to create a meaningful dialogue between NHS personnel and Gypsy and Traveller communities – but will need to be adequately resourced.

Entitlement to NHS care

Many Gypsies and Travellers have lived in the UK for centuries (though some Roma Communities have arrived more recently, many in the last 20 years) and therefore have a right to NHS services. PCTs are reminded that entitlement to NHS care in the UK is based on residency, rather than having a permanent postal address: as such, Gypsy and Traveller communities have the same rights of access to NHS services as any other citizen.

Cultural awareness

PCTs with Gypsy and Traveller communities should consider including cultural awareness training as part of their regular mandatory training for all new and existing staff. This should be geared towards conveying what it is actually like to be a Gypsy or Traveller, including their enduring legacy of discrimination and disadvantage, their culture, family life, health needs and so on.

Additional resources – see Annex 2

2. Purpose of this primary care service framework

This PCSF is not about providing different or separate services for Gypsies and Travellers; rather, it is about ensuring that these communities can access the same high quality, mainstream primary care services as everyone else. It may be used to assist PCTs to design new services where none exist or to adapt or front-end existing ones to make them accessible to these groups.

There is evidence³ that Gypsies and Traveller communities experience more poor health than any other disadvantaged group living in England. Many Gypsies and Travellers are settled. The health needs of settled Gypsies and Travellers are every bit as bad as that of mobile Gypsies and Travellers. The purpose of this framework is therefore:

- to equip PCT commissioners, with the necessary background knowledge, service and implementation details to work with providers and practitioners to deliver accessible primary care services, over and above mainstream services, for Gypsy and Traveller communities
- to improve Gypsy and Traveller health and quality of life by providing effective, appropriate, ongoing support, recognising three key factors:
 1. the need to improve Gypsies and Travellers' access to GP and primary care services, because without the same sort of access enjoyed by the general population, the health status of Gypsies and Travellers is likely to remain poor.
 2. cultural issues relating to Gypsy and Traveller communities that impact on their access and use of health services, for example, the strong traditional gender roles.
 3. lack of cultural awareness on the part of health service providers can form a barrier to accessing services for Gypsies and Travellers

3. Period of service

It is recommended that this service is commissioned for a minimum period of 3-5 years initially, subject to satisfactory annual review. This is for the following reasons:

- Most PCTs have little information about the Gypsy and Traveller communities living in their area. Lack of a proper needs assessment is not sufficient excuse for lack of provision, and one of the key objectives of this PCSF (see section 8 below) is to build a better information base about the population(s) being served. This will take time to achieve.
- Key to success is building trust and understanding with local Gypsy and Traveller communities, and to

³ The Health Status of Gypsies & Travellers in England, University of Sheffield Report, 2004

overcome their cynicism that is, perhaps, the inevitable result of prejudice and a long history of poor access to the NHS. Likewise, this will take time to achieve.

- Stability and continuity of services are important.
- It will also take time for any new/extended services to become established
- To ensure a viable contract term for providers – any contract that runs for a shorter period than that described above is unlikely to allow the providers sufficient time to develop and establish the service and will not give continuity of care for users.

4. Scope and definition of service

- **Scope:** this PCSF is for mainstream primary care services aimed at Gypsies and Travellers (see Preface for the various groups included) whether mobile or settled. Outreach and advocacy services may also be included.
- **Service location:** the service is to be provided in a primary care location. It is likely that many services will be provided from their current location(s), at PCT, locality or practice level. Outreach preventive services, and mobile public health campaigns may be appropriate, but they should never be used as substitutes for effective mainstream services. Care is needed to avoid a “ghetto” approach (see section 9) where services for Gypsies and Travellers are concentrated in one location with a single provider
- **Providers:** The services are open to all types of provider, eg GP practices, dental practices, community and specialist nurse-led services, voluntary sector, Local Authority, the independent sector or other alternative providers.

This primary care service framework should not be confused with (and sits outside of) essential and additional GMS or PMS services already provided, current Quality and Outcomes (QOF) indicators and any National Enhanced Services. Commissioners are reminded of their requirements to adhere to the respective Regulations and APMS directions.

5. Parties to the agreement

For example:

Names of any accountable individuals and organisation details.

6. Background

Results of the 2004 University of Sheffield Report “The Health Status of Gypsies & Travellers in England “ <http://www.shef.ac.uk/content/1/c6/02/55/71/GT%20report%20summary.pdf> found that Gypsies and Travellers have significantly poorer health status and significantly more self-reported symptoms of ill-health than other UK-resident, English speaking ethnic minorities and economically disadvantaged white UK residents. The Report concluded that the scale of health inequality between Gypsies and Travellers and the UK general population is large, with reported health problems between twice and five times more prevalent.

The following is an extract from the Executive Summary of the Report:

“ Health status in the Gypsy Traveller group is correlated with those factors that are recognised as influential on health: age, education and smoking. However the poorer health status of Travellers can not be accounted for by these factors alone. Gender differences were found; women were twice as likely as men to be anxious, even when education, smoking and carer status was taken into account.

The aspects of Gypsy Traveller health that show the most marked inequality are self-reported anxiety, respiratory problems including asthma and bronchitis, and chest pain. The excess prevalence of miscarriages, stillbirths, neonatal deaths and premature death of older offspring was also conspicuous. There was less inequality observed in diabetes, stroke and cancer.

Travellers’ health beliefs and attitudes to health services demonstrate a cultural pride in self-reliance. There is stoicism and tolerance of chronic ill health, with a deep-rooted fear of cancer or other diagnoses perceived as terminal and hence avoidance of screening. Some fatalistic and nihilistic attitudes to illness were expressed; that is, illness was often seen as inevitable and medical treatment seen as unlikely to make a difference. There is more trust in family carers rather than in professional care.

In relation to Gypsy Travellers’ experiences in accessing health care and the cultural appropriateness of services provided, we found widespread communication difficulties between health workers and Gypsies and Travellers, with defensive expectation of racism and prejudice. Barriers to health care access were experienced, with several contributory causes, including reluctance of GPs to register Travellers or visit sites, practical problems of access whilst travelling, mismatch of expectations between Travellers and health staff, and attitudinal barriers. However, there were also positive experiences of those GPs and health visitors who were perceived to be culturally well-informed and sympathetic, and such professionals were highly valued.

Fewer than half of the PCTs, SHAs and PHOs responding to our survey had knowledge of the numbers or location of Gypsy Travellers locally. Information on Gypsy Travellers’ use of services was more rarely available and only a fifth had any specific service provision. Only one in ten had any policy statement or

planning intentions that specifically referred to Gypsy Travellers.

Our findings confirm and extend the practice-based evidence on poorer health in Gypsy Traveller populations. There is now little doubt that health inequality between the observed Gypsy Traveller population in England and their non-Gypsy counterparts is striking, even when compared with other socially deprived or excluded groups and with other ethnic minorities.

The impact of smoking, education and access to GP service is important. The educational disadvantage of the Travellers was extremely striking, and the single most marked difference between Gypsy Travellers and other socially deprived and ethnic minority populations. However, these factors do not account for all the observed health inequalities. The roles played by environmental hardship, social exclusion and cultural attitudes emerge from the qualitative study, and are consistent with the finding there is a health impact of being a Gypsy Traveller over and above other socio-demographic variables.”

“Some implications of our research findings for health policy and provision are drawn out. These include:

- Methods are needed to improve access to, and cultural safety of, health services for Gypsies and Travellers.
- Working in partnership with Gypsy and Traveller communities in the delivery of health care would be both possible and effective.
- Commissioning dedicated or specialist health workers, including their community development and liaison role, would be welcomed by Gypsies and Travellers.
- Improving the cultural competence of health service staff is a priority, to combat racist and discriminatory attitudes based on ignorance or fear, which feed into defensive hostility and promotes communication difficulties. Any developments in cultural safety training should be evaluated.
- Better coverage of Gypsies and Travellers in NHS ethnic monitoring would address their ‘invisibility’ in public health terms.
- Primary Care Trusts may value advice on overcoming the difficulty faced by Gypsies and Travellers in obtaining GP registration.
- Primary Care Trusts and Strategic Health Authorities have an opportunity to address this issue in their Health Equity Audits by 2006.
- As many of the determinants of health status are outside the remit of the Department of Health,
- inter-Departmental co-ordination with regard to Gypsy and Traveller health seems advisable. “

7. Summary of local need

For example:

A detailed summary of local health and social care service needs drawn from a Joint Strategic Needs Assessment, done with Local Authority partners. Valuable information may also be drawn from Gypsy and Travellers Accommodation Needs Assessments, which are statutorily required from local authorities. Local education departments are also good sources of information about the needs and circumstances of Gypsy and Traveller families.

8. Service aims, principles, objectives and outcomes

Aims

The overall aim is improve access to primary care services for Gypsy and Traveller communities through the provision of a service that is more accessible and appropriate to the needs of these communities Better access is likely to lead to improved health outcomes.

Principles

The following principles should guide service development as these will support Gypsy and Traveller services to access responsive primary care services :

Partnership working: Given the wider determinants of health such as accommodation and sanitation, partnership working with Local Authorities is critical if NHS services are to be successfully established and delivered. Effective engagement with community members is especially important in relation to Roadside Gypsies and Travellers, who may otherwise miss out on screening, immunisation or other services.

Community involvement: Local Gypsy and Traveller Communities should be involved in developing new services or adapting/front-ending existing services; this engagement should be properly resourced and care should be taken to avoid tokenism. A key part of this involvement should involve listening and responding to the stories and views of their own local communities as part of the needs assessments and EqIA

Accessibility to mainstream services: A “ghetto” approach (where Gypsy and Traveller only services are concentrated in particular locations or delivered by a single provider) should be avoided. Instead PCTs should focus on enabling Gypsy and Travellers to access mainstream services in the same way as any other citizen is able to. It is also important that Gypsies and Travellers are wherever possible fast-tracked into primary care services – recognising the fact that they may be forced to move on, and thereby be denied

access

Specific objectives

The specific objectives of the service should be to:

- To provide better mainstream NHS primary medical care services to meet the particular health needs of the Gypsy and Traveller communities
- Involve the communities being served in the design and review the service
- Build a better information base about the health needs of Gypsies and Traveller communities in the locality
- Enable Gypsies and Travellers to access services easily
- Include particular services that are targeted to the population's needs
- Ensure access to appropriate advocacy services. *“Advocacy can help service users to:*
 - *make clear their own views and wishes;*
 - *express and present their views effectively and faithfully;*
 - *obtaining independent advice and accurate information;*
 - *to take more responsibility and control for the decisions which affect their lives”*⁴
- Review care pathways from a Gypsy/Traveller perspective to ensure barriers and blocks to access are identified and removed.

Outcomes

The intended health outcomes are to:

- provide empathetic services which take account of the cultural issues relating to the communities being served
- improve the accessibility and take up of services, to reduce health inequalities
- promote sustainability by establishing a learning and reflective environment that includes activity to share/ transfer learning to the wider NHS (both locally and beyond)

⁴ Taken from: <http://www.cambridgeshire.gov.uk/NR/rdonlyres/319F70A9-C8D0-4AEB-81B1-D747E8959EC5/0/Whatisadvocacy.pdf>

9. Service outline

GP services

To avoid creating isolated Gypsy and Traveller only practices, it is strongly recommended that the adaptations/flexibilities below are commissioned from all practices in the PCT or in a given locality. PCTs should also monitor practice boundaries, to check these are not being re-drawn to exclude Gypsy and Traveller sites.

- **Registration:** Practices should have a policy of registering Gypsies and Travellers as Fully Registered patients wherever possible, rather than as Temporary Residents. People who travel away within the UK (for up to 6 months) should not automatically be de-registered (see Annex 5)
- **Walk-in appointments:** Practices should adopt a policy of not turning away any Gypsy/Traveller who attends without an agreed appointment, even if all appointments for that day are full.
- **Longer consultations:** Practices should allow up to 20 minutes for consultations. Any requests to see other family members in the consulting room should be agreed (within reason), as this provides an opportunity to improve the screening status of potentially vulnerable patients.
- **Screening, child health surveillance & immunisations:** given the fact that mobile Gypsies and Travellers may be forced to move on from unauthorised sites, as well as travel of their choice, it is likely that Gypsies and Travellers will not be as reliable as the settled population in keeping or making appointments. Using SMS text messaging software to send reminders may be useful here. The PCT may wish to make allowance for the consequent impact on a practice's QoF points; for instance a practice may find it hard to achieve maximum QoF points if some patients do not attend at the specified intervals for immunisations
- **Records:** practices should use a special flag to identify Gypsy and Traveller records, and apply Read Codes to all identified Gypsies and Travellers (it is important to record ethnic status as Gypsies and Travellers are not currently included in the official list of ethnicity codes). The department of health has produced "A Practical Guide to Ethnic Monitoring in the NHS and Social Care" http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4116839) which advises PCTs to use the ethnicity codes from the 2001 census. If these codes are disaggregated locally to take account of significant local populations this should be done in such a way that the disaggregated codes can be built back up to the census codes. Otherwise it would be difficult to carry out comparisons between patient ethnicity profiles and the local population. Consideration should be given to:

- Developing a template for collecting health information on Gypsies and Travellers
 - Making summary printouts available for people to take with them when they go travelling. (NB Particular care is needed here to avoid confidentiality errors).
- **Patient information:** Provision of Gypsy and Traveller-friendly leaflets and health promotion material.
 - **Cultural awareness training:** this should be mandatory for all doctors and practice-based staff. This training should be planned and delivered by community members working in partnership with, and supported by, staff from the PCT or another service.
 - **Outreach:** this could take the form of a practice-based outreach worker/advocate, (or a nurse) with responsibility for
 - visiting sites regularly to provide health information and promote proactive health care and facilitate access to mainstream services
 - encouraging screening and full GP registration
 - liaison with other community staff serving the Gypsy and Traveller communities
 - promoting cultural awareness within the GP practice
 - monitoring Gypsy and Traveller views of services being provided.

Outreach services

In addition to the above, PCTs may wish to commission an outreach service to enable Gypsies and Travellers to access services. This should operate both ways (ie inreach as well as outreach) in order to help bridge the gap between Gypsy and Traveller communities and the settled population. The SureStart model (www.surestart.gov.uk) may offer a useful approach/learning here. It is important that the local Gypsy and Traveller communities should be involved in choosing/agreeing who is appointed to these posts.

Advocacy

This may be commissioned at either individual or strategic level (see Annex 4 for Leeds GATE job description). The community being served should be involved in the selection of advocates. Care should be taken to ensure that the use of advocacy does not become a substitute for the ongoing development of the required skills for all staff working within the service.

Recruitment issues

Involving community members in recruitment needs to be genuine and can take time to develop (both in terms of community capacity and professional empowerment capacity skills). Not all PCTs will have existing relationships/links which can easily be built on, and may need to link into other areas where community

members are familiar with this process to ensure timely recruitment.

Named PCT lead

It is recommended that the PCT has a named lead for Gypsy and Traveller Health. This should be a senior manager.

10. Location of service

If the service is to be provided from existing premises, details should be included here.

Whilst mobile units can be effective for preventive/screening campaigns, PCTs should note that these are not an effective substitute for properly front-ending or adapting existing mainstream primary care services. Inappropriate use of mobile units can reinforce or even worsen existing prejudices.

Using existing community based venues - where people and patients are already familiar with the environment – can be very helpful. However, PCTs should bear in mind that the important thing is effective signposting into mainstream services by advocates.

11. Integrated governance

Clinical governance arrangements must be proportionate to the service provided and comply with any local expectations or requirements of the commissioner.

Any commissioned service must meet all national standards of service quality and clinical governance including those set out in Standards for Better Health (http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4086665). These core and developmental standards of provision are designed to cover the full spectrum of health care as defined in the Health and Social Care (Community Health and Standards) Act 2003. The seven domains are safety, clinical and cost effectiveness, governance, patient focus, accessible and responsive care, the care environment and public health. Compliance with relevant NICE guidance is also required.

Professional competency, education and training – All healthcare professions delivering the service will be required to demonstrate their professional eligibility, competence, and continuing professional development in order to remain up-to-date and deliver an effective service which is culturally appropriate. Staff appraisal on an annual basis and at an appropriate level will also be required. Commissioners will need to be reassured that practitioners have the required competencies at an appropriate level. Specifically cultural awareness training should be delivered, preferably in conjunction with the communities being serviced.

Commissioners should be satisfied that providers who deliver the services described have a planned, regular programme of education, training and support for their staff, extended team and community networks in matters related to their programme(s).

Providers should ensure safe staffing capacity at all times and staff should be able to demonstrate that they have participated in organisational mandatory and update training, for example infection control, manual handling, risk assessment as required.

Patient, public and staff safety – Providers will be required to demonstrate that evidence based clinical guidelines are being used. Providers should have in place appropriate health and safety and risk management systems and that premises standards are met. They should also ensure that any risk assessments and significant events are both documented and audited regularly and outcomes of these implemented. Services should comply with national requirements for recording, reporting, investigation and implementation of learning from incidents. Further details can be found on the National Patient Safety Agency website www.npsa.nhs.uk

The provider of this service is also required to have in place effective policies and procedures which promote the well being and safety of service users and staff. Providers should ensure safe staffing capacity at all times and staff should be able to demonstrate that they have participated in organisational mandatory and update training, for example infection control, manual handling, risk assessment as required.

Information management – Any communications strategy or provision should be coherent with and follow local policies and the Department of Health Code of Confidentiality, local child and adult protection procedures, and should outline the mechanisms to safeguard patient information when shared within an integrated service.

Clinical audit and review – Providers will be required to demonstrate their coordination of and involvement in regular inter-professional and inter-agency meetings and regular clinical audit of the service interventions and outcomes such as drug therapies or well-being and behaviour changes. This audit can be carried out by extracting data using the Read codes.

Patient and public involvement - Providers will be required to demonstrate active engagement with patients and local communities in commissioning and developing services, self care plans or in supporting patients to utilise self care opportunities. Providers should demonstrate how systematic patient feedback is being used to shape and improve services. Involving family carers and supporters will help deliver the components within this service specification. Local Involvement Networks (LINKs), the voluntary sector and patient advocacy organisations are all further mechanisms to seek active involvement in service planning, delivery and monitoring.

Managing complaints – Responsive protocols and procedures should be in place for managing patient complaints. These should be available in 'easy read' (or even in an easy 'taken as verbal') format so they are

accessible to people with limited communication skills. Complaints should be reviewed at regular intervals and learning from these shared and applied as appropriate to ensure that services are continually improved. A sign of an effective complaints system is that it is used; this is a good way to engage Gypsy and Traveller people initially. An easy to use complaints system which rapidly produces visible outcomes may go a long way to raising trust amongst community members. This could be the first plank of a bridge of communication and should be viewed positively.

Continuous quality improvement – a set of indicators should be selected or developed and then agreed which defines the key quality requirements of the service. The service should also identify how it uses these measures and others to ensure that the quality of the service is continuously improved.

12. Information management/requirements, including health records (see also section 9)

PCTs should apply the principle that broadly the same data should be collected from practices on Gypsies and Travellers as for other residents in their area. PCTs may require providers to collect some additional information to enable them to monitor the delivery of the service and to inform the longer-term development of services. The data collection should sit alongside and not duplicate information collection requirements where they are already incentivised through the QoF or the new Directed Enhanced Service for ethnicity and first language which due to be introduced and for which GPs will be rewarded for 50% (first year) and 90% (second year) completion rates.

The aim of this dataset is to:

- build a better information base about the health needs of Gypsies and Traveller communities in the locality, and thus inform the longer-term development of primary care services. Bearing in mind that the next full Census of England and Wales (which is likely to include a code for “Gypsies and Travellers” for the first time) will not take place until 2011, a starting point might be to collect information about who is living in the PCT’s area – numbers of people, age, gender and ethnicity. Information about long terms conditions may also be useful (see 9, Service Outline, records above for further guidance on use of census codes) PCTs may also find it helpful to refer to work undertaken in Leeds in 2004 and 2005 to enumerate the local Gypsy and Traveller communities, “Gypsies and Travellers Leeds Baseline Census 2004-2005” (<http://www.gypsyromatravellerleeds.co.uk/information/academicStudies.html>).
- Enable them to monitor the performance of individual providers
- Assist in the identification of service pressures and gaps
- Support public health mapping

Health records: the mobility of some Gypsies and Travellers, as well as differing traditions regarding use of surnames, means that how their health records are handled will need careful consideration. There are two

main approaches:

- Hand held, including summary printouts – being piloted in West Midlands & South East Coast regions as part of the Department of Health-funded Pacesetters programme. Hand held records are already used in Ireland and Scotland.
- Family held - these can have the advantage of avoiding confusion regarding names

Providers will need to think carefully about record keeping pending the outcomes of the Pacesetters pilot. Use of a flag in the GP record for Gypsies and Travellers may be useful.

GP registration: full registration with a GP in the area where the Gypsy or Traveller spends most of his/her time should be encouraged, but not made mandatory.

Communications and patient information: PCTs should be aware of the educational disadvantage of some Gypsies and Travellers and design their communications accordingly. Using emails and text messaging is often better than letters. However, PCTs should note that whilst internet use is rapidly increasing amongst those with some literacy it is still not widespread. Email is useless, and potentially may cause breach of confidentiality problems, where the patient is not literate. In such situations, emails could perhaps be used via patient-named advocates - but there would need to be an awareness of time resources. Any information leaflets should use simple language, with pictures and diagrams. Leaflets should, if at all possible, be taken to a focus group before being finalised.

PCTs should note that under the Disability Discrimination Act, NHS bodies have a legal duty to provide information on its services to all communities in appropriate languages and formats. If PCTs prefer to include this as a requirement for providers to carry out rather than the PCT, then the costs of production may need to be reflected in the costs of the service agreed with the providers.

13. Service monitoring and evaluation

Monitoring and evaluation of the services should sit within the PCTs contract monitoring cycle. Service providers will need to demonstrate the effectiveness of the service to commissioners possibly at regular times during the year and, at the least, on an annual basis. This will need to be provided to the commissioners in an annual report, which will inform any annual review process or meeting. The process by which this evaluation is achieved can also be used to show the outcomes of the service to other key stakeholders such as users and family carers. PCTs will need to take into account the fact that new services will need time to become familiar with the client group and begin to gain their trust. Therefore initial progress may be slow. This will not necessarily mean there is no progress. Service evaluation should be built in from the commencement of any service and should cover, as a minimum, the following areas:

- **Service activity** – Volume of work against any agreed activity levels and distance from profile, capacity, needs and demand analyses, workforce arrangements, real time referral data to other care pathways or appropriate agencies recorded appropriate Read codes.
- **Clinical outcomes** – Regular analysis and interpretation of clinical outcomes data as well as regular analysis and interpretation of PPA data for prescribing.
- **Quality and governance** – Quality criteria will need to be established (in agreement with commissioners) and measured with standards needing to be met on a continual basis. Results of clinical audits will be used to inform service provision during the year. EqlA data should be used to underpin local integrated service provision.
- **Patient experience** – Patients' views on their experiences and satisfaction levels will need to be measured through an on-going, systematic process to test whether the service is engaging with patients, family carers and supporters in a way that supports them. Different and innovative approaches to obtaining these views and experiences will be necessary, eg through capturing stories of community members experiences of the NHS and applying the learning from these. These processes should also be stratified where possible to show any differential impact on disadvantaged groups (e.g. Black and Minority Ethnic groups, deprived groups, males, females etc) and any resultant service changes (planned or achieved) should be highlighted.
- **Value for money** – Cost effectiveness or 'best value' analyses of the primary service outcomes in relation to comparative costs of hospital activity or those services providing equivalent quality of care. Such measures could include attendance rates, waiting times. Other possible analyses include: - prescribing costs; benefits of increase in social capital and active citizenship; Staff and non-staff costs of running the service; capital costs etc.

14. Funding

There will be no fixed or nationally agreed price for this service. Commissioners and providers may wish to access alternative funding mechanisms, and should agree funding which is reflective of the level of service to be delivered locally and could include:

- Basic funding for achieving minimum requirements within the service specification
- Additional funding or financial incentive for delivering specific local patient outcomes
- Indication of national benchmark prices if available

15. Contract management

For example:

Name and contact point of the contract manager of both the commissioner and provider. Any specific local arrangements for contract management should also be stated.

16. Review, variation and re-commissioning process

For example:

- Formal review of the service
- Contractual variation procedures
- De-commissioning and re-commissioning arrangements
- Notice periods
- Dispute Resolution and Arbitration procedures
- Legal advice and support

17. Signatories

Signatures from both parties as those accountable for the agreement

Extract from NHS Act 2006**242 Public involvement and consultation**

- (1) This section applies to—
- (a) Strategic Health Authorities,
 - (b) Primary Care Trusts,
 - (c) NHS trusts, and
 - (d) NHS foundation trusts.
- (2) Each body to which this section applies must make arrangements with a view to securing, as respects health services for which it is responsible, that persons to whom those services are being or may be provided are, directly or through representatives, involved in and consulted on—
- (a) the planning of the provision of those services,
 - (b) the development and consideration of proposals for changes in the way those services are provided, and
 - (c) decisions to be made by that body affecting the operation of those services.
- (3) For the purposes of this section a body is responsible for health services—
- (a) if the body provides or will provide those services to individuals, or
 - (b) if another person provides, or will provide, those services to individuals—
 - (i) at that body's direction,
 - (ii) on its behalf, or
 - (iii) in accordance with an agreement or arrangements made by that body with that other person,
 and references in this section to the provision of services include references to the provision of services jointly with another person.
- (4) Subsection (5) applies to health services for which a Strategic Health Authority is not responsible by virtue of subsection (3), but which are or will be provided to individuals in the area of the Strategic Health Authority, and for which—
- (a) a Primary Care Trust any part of whose area falls within the Strategic Health Authority's area, or
 - (b) an NHS trust which provides services at or from a hospital or other establishment or facility which falls within the Strategic Health Authority's area,
- is responsible by virtue of subsection (3).
- (5) A Strategic Health Authority may give directions to Primary Care Trusts falling within paragraph (a) of subsection (4), and NHS trusts falling within paragraph (b) of that subsection, as to the arrangements which they are to make under subsection (2) in relation to health services to which this subsection applies.

243 The Commission for Patient and Public Involvement in Health

- (1) There continues to be a body corporate known as the Commission for Patient and Public Involvement in Health ("the Commission") to exercise the functions set out in subsections (2) to (5) (in addition to its function of appointing members of Patients' Forums).
- (2) The Commission has the following functions—
- (a) advising the Secretary of State, and such bodies as may be prescribed, about arrangements for public involvement in, and consultation on, matters relating to the health service in England,
 - (b) advising the Secretary of State, and such bodies as may be prescribed, about arrangements for the provision in England of independent advocacy services,

- (c) representing to the Secretary of State and such bodies as may be prescribed, and advising him and them on, the views, as respects the arrangements referred to in paragraphs (a) and (b), of Patients' Forums and those voluntary organisations and other bodies appearing to the Commission to represent the interests of patients of the health service in England and their carers,
 - (d) providing staff to Patients' Forums established for Primary Care Trusts, and advice and assistance to Patients' Forums and facilitating the co-ordination of their activities,
 - (e) advising and assisting providers of independent advocacy services in England,
 - (f) setting quality standards relating to any aspect of—
 - (i) the way Patients Forums exercise their functions, and
 - (ii) the services provided by independent advocacy services in England, monitoring how successfully they meet those standards, and making recommendations to them about how to improve their performance against those standards,
 - (g) such other functions in relation to England as may be prescribed.
- (3) It is also the function of the Commission to promote the involvement of members of the public in England in consultations or processes leading (or potentially leading) to decisions by those mentioned in subsection (4), or the formulation of policies by them, which would or might affect (whether directly or not) the health of those members of the public.
- (4) The decisions in question are those made by—
- (a) health service bodies,
 - (b) other public bodies, and
 - (c) others providing services to the public or a section of the public.
- (5) It is also the function of the Commission—
- (a) to review the annual reports of Patients' Forums made under section 240, and
 - (b) to make, to the Secretary of State or to such other persons or bodies as the Commission considers appropriate, such reports or recommendations as the Commission considers appropriate concerning any matters arising from those annual reports.
- (6) If the Commission—
- (a) becomes aware in the course of exercising its functions of any matter connected with the health service in England which in its opinion gives rise to concerns about the safety or welfare of patients, and
 - (b) is not satisfied that the matter is being dealt with, or about the way it is being dealt with,
- the Commission must report the matter to whichever person or body it considers most appropriate (or, if it considers it appropriate to do so, to more than one person or body).
- (7) Bodies to whom the Commission might report a matter include—
- (a) the regulatory body for the profession of a person working in the health service,
 - (b) the Commission for Healthcare Audit and Inspection.
- (8) The Commission may make such charges as it considers appropriate for the provision of advice and other services (but this is subject to any prescribed limitation).
- (9) The Secretary of State may by regulations make further provision in relation to the Commission.
- (10) The regulations may, in particular, make provision as to the provision of information (including descriptions of information which must or must not be provided) to the Commission by a Strategic Health Authority, a Primary Care Trust, an NHS trust, a Special Health Authority, an NHS foundation trust, a Patients' Forum or a provider of independent advocacy services.

(11) Schedule 16 makes further provision about the Commission.

(12) In this section—

“carer” and “patient” have the same meaning as in section 237,

“the health service” includes services provided in pursuance of section 75

arrangements in relation to the exercise of health-related functions of a local authority,

“health service bodies” means Strategic Health Authorities, Primary Care Trusts, NHS trusts and NHS foundation trusts,

“independent advocacy services” means services provided under section 248,

“section 75 arrangements” means arrangements under regulations under Section 75

Additional Resources

DDLG mental health survey report and elderly survey. The full report will be released in due course entitled 'I Know When it's Raining' www.lglg.co.uk/page3.htm

Aiming Higher (Dr Margaret Greenfield)

Setting up a GP Enhanced Service for Travellers (Dr Nick Leach FRCGP, Market Harborough Medical Centre, April 2008) - included as Annex 3

Unequal health: a world class NHS? Yorkshire and Humber BME Regional Panel, *Strategic Voice for Voluntary and Community Sector* www.bme.org.uk, September 2008

Details of NHS charges (prescriptions, surgical supplies, dental and optical services) and help with health costs,

<http://www.dh.gov.uk/en/Healthcare/Entitlementsandcharges/NHSCcharges/index.htm>

See also NHS Act 2006 - sections 242 & 243 are reproduced in Annex 1

<http://www.raceequalityfoundation.org.uk/health/files/health-brief12.pdf>

Market Harborough Medical Centre

Setting up a GP enhanced service for Travellers:

Previous experience

Prior to the development of our enhanced service, the practice experienced a series of problems relating to the two large and one small traveller sites in our catchment.

Reception issues

As will be common with many practices, the demands of the QOF have put pressure on access to GPs, since the requirement for extra monitoring and follow up of patients with chronic disease has increased overall workload very considerably.

To offset this increase, and release the doctors in the practice to concentrate on their core activity of problem solving, a sophisticated appointment system was developed. Patients could be directed into clinics run by highly trained nurses for monitoring of chronic diseases, while at the same time minor illness was directed to specialist nurse triage clinics. These innovations worked well in relieving pressure on access to the GPs but they relied heavily on telephone pre booked appointments.

Unfortunately, Travellers have tended to attend the surgery without a pre booked appointment. They come to the desk and ask to see the doctor. The receptionist will offer them a next available appointment; perhaps the following day, but they insist they need to see the doctor that day. Usually, by that time, all the day's non urgent appointments are already booked. An argument was then likely to follow as to whether the Traveller's condition was urgent or not.

However well meaning the protagonists were, these circumstances were likely to result in conflict, resulting in the Traveller storming out, angry and untreated, or the receptionist upset, or a doctor angry that he/she was being asked to see a non urgent problem as an urgent.

Morbidity issues

At the same time, we had become aware that our Traveller patients were a very vulnerable group. Despite not having seen any official statistics, it was apparent to our doctors that the traveller population suffered more premature death from respiratory and heart disease than the rest of our patients, male travellers particularly suffered an excess of mental health and alcohol related problems.

Cancers presented too late for effective treatment.

There was also an alarming amount of road accidents and other trauma and serious childhood infections. The one area that appeared better in Travellers, was the lack of problems among the frail elderly that we experienced with the rest of our population. It then occurred to us that the reason for this "benefit" was that very few Travellers seemed to reach an age when such problems occurred.

Consultation issues

When Travellers finally reached the doctor's consulting room, further problems emerged.

Most Travellers were seen as Temporary Residents. This was partly because of a reluctance on the part of many Travellers to fill in registration forms and have information about them to be collected on file, but largely because we had been concerned that if we registered Travellers as fully registered patients our target payments and QOF points might be adversely affected.

Our experience was probably similar to other practices in finding that Travellers were not as reliable as the resident population in maintaining their vaccination status, cervical cytology and screening and monitoring of chronic conditions.

This was further exacerbated by the mobile nature of Travellers who may not be at their supposed address to receive invitations or reminders to come for screening, monitoring or prevention. In addition it was common for Travellers to have reading problems such that response to written invitations was likely to be poor.

The consequence of Temporary Resident status is that no up to date medical records are available or maintained. Often Travellers will have been temporary residents at previous practices, so that no one could be found with a comprehensive past medical record. The doctors often mistrusted the Travellers' own accounts of their previous medical history and there was often confusion over the provenance of previous diagnoses or the appropriateness of declared medication. This could result in either continued

management based on uncertain evidence, or the need to repeat tests and investigations, perhaps unnecessarily, at cost to the health budget and the patient.

The difficulty Travellers had in accessing the doctors consulting room gave rise to another problem phenomenon; it was common for the patient, having finished with her own problem, then to ask the doctor if he/she could also have a quick look at one, two, three or more children with varying problems.

These difficulties all conspired to make the doctor feel stressed by the uncertainty surrounding the care of Travellers' health, and angry and intolerant of the requests for extra consultations with the children. This in its turn tended to be felt by the Travellers, who had perhaps previously experienced racial prejudice, as showing that the doctor was uncaring or hostile.

Solutions

We had the advantage of having a specialist health visitor who was highly experienced in interacting with Travellers, and who enabled us to see that these problems were not due solely to the day to day culture of the Travellers but was also contributed to by the fairly rigid structure of the health service we provided. We had spent many years trying to change the behaviour of Travellers, with total lack of success; if we wanted to resolve these problems we should start learning to change our own behaviour.

Proposals

We resolved to make a number of changes in practice policy. The cost of the changes would then be assessed and we would apply to the PCT for a local enhanced service that would enable us to recoup the costs.

- 1 We would have a policy of registering as many Travellers as possible as fully registered patients.
- 2 We would not turn away any Traveller without a consultation or an agreed appointment, even if all appointments were full.
- 3 We would accept any requests to see other family members in the consulting room as an opportunity to improve the screening status of a potentially vulnerable patient.
- 4 We would apply a Read Code to all identified Travellers, whether resident of a site or a house. [since they are still not included in the official list of ethnicity codes]
- 5 We would use a template for collecting health information on Travellers
- 6 Having set up medical records for our Travellers, we would make summary print outs available to those with significant chronic illness to take with them when they went travelling. But we would have to be familiar with the traveller in order to avoid confidentiality errors.
- 7 We would appoint and train a practice nurse to visit Traveller sites twice weekly to provide health information and encourage screening, proactive health care and full registration [but not to provide actual health care on site; we did not want to promote an "ghetto" service]
- 8 We would hold Traveller forums to monitor users views of the service provided.
- 9 As we became more experienced, we would provide training to community staff and liaison with local school nurses serving the Traveller community.
- 10 We would not de-register Travellers who travelled away for up to six months.
- 11 Women Travellers who attended would be actively encouraged to persuade their men folk to attend for screening or early diagnosis and treatment.
- 12 Provision of Traveller-friendly leaflets and health promotion literature.
- 13 Male doctors would be prepared to visit sites to encourage older men to attend surgery for screening and early diagnosis.

Costs

Depending on economies of scale, the cost of the scheme came to about £100 per Traveller in the catchment population.

This appears a lot, but it comprises a series of features:

- 1 Likely loss of target payments
- 2 Likely loss of QOF points
- 3 Increased staffing to enable elasticity in appointments
- 4 Increased doctor hours to enable extra consultations
- 5 Cost of employing and training a specialist practice nurse undertaking on site sessions.
- 6 Staff and doctor hours expended in planning, administration and communications
- 7 Administrative, IT and stationery costs.

Outcomes

So far we have increased full registration to about half of the estimated Traveller population in the area at any one time.

Stress among reception staff has decreased considerably, since they no longer have to say "no" to any Traveller asking for a consultation.

Increasing trust from Travellers has been gratifying to experience. The women are beginning to come for regular screening and the use of our Child Health Surveillance clinics and immunisation clinics has been increasing steadily.

Travellers sometime drive considerable distances to attend our surgery when away travelling but need to see a doctor they feel they can trust.

Traveller forum attendance has been entirely female so far.

We still have a long way to go in persuading older male Travellers to come early, particularly when they fear cancer. There is a fatalistic attitude to cancer that delayed requests for help until it is often too late for successful treatment.

Dr.Nick Leach FRCGP
Market Harborough Medical Centre

April.2008

JOB DESCRIPTION: Gypsy/Travellers Health Advocate

Area of work:	Leeds
Accountable to:	Director
Report to:	Director/Management Committee
Salary:	
Hrs:	35hrs per week
Contract:	

Job Summary

To improve Gypsies and Travellers access to health care provision, health promotion and other related services in Leeds by providing individual advocacy support, targeted casework to highlight issues as well as general signposting and improving access to information.

To work with and support Gypsies and Travellers to lobby for changes in health provision at an operational, strategic and policy level that will contribute to improving the health of the whole community in Leeds

DUTIES:

1. To provide intensive support/casework to targeted families or individuals as a way of raising concerns or improving the practice of health providers.
2. To be accessible to all Gypsy and Travellers by providing weekly drop in advocacy sessions across the city at agreed venues and times.
3. To advocate on behalf of individual Gypsy and Travellers with health providers and other key agencies using appropriate means of communication
4. To accompany individual Gypsy and Travellers to appointments and other meetings as necessary
5. To make home visits to Gypsy and Travellers living on the roadside, the Cottingley Spring site and to those living in houses as necessary
6. To identify key health issues affecting particular groups of Gypsy and Travellers and to work with community representatives to highlight their concerns with service providers and to negotiate for improved services.
7. To develop and maintain networks with health service providers and managers statutory, voluntary and community organisations as appropriate for the development of the health advocacy service.
8. To contribute to health assessment audits and other research to further identify the health needs of Travellers
9. To contribute to and represent the interests of Gypsies and Travellers on health related working groups or forums to ensure the particular needs of the communities are considered and included in new health policies, strategies, new initiatives as well as action plans such as the Race Equality Scheme.

10. To work with Gypsies and Travellers, health providers and other stakeholders to identify medium and long-term strategies to address the health needs of the community and to produce a 3-year plan of action for the scheme.
11. To contribute to the training of health providers around the cultural and health needs of Gypsies and Travellers.
12. To maintain agreed written records of all work carried out for monitoring and evaluation purposes, and to contribute to the development and review of the health advocacy scheme.
13. To produce written and verbal reports on the scheme reflecting outcomes and outputs as maybe required by the funders or the Director of GATE.
14. To keep informed, and engage with as agreed by line manager, of local, regional and national developments and initiatives that may have an impact on the health provision of Gypsy and Travellers.
15. To ensure that a professional confidential service is provided that treats clients with courtesy, respects their right to self determination and adheres to the principles of advocacy

General

16. To adhere to the personnel, financial and other policies and procedures of GATE
17. To participate in supervision, training and appraisal as agreed with the Director
18. To be responsible for ones own health and safety at all times taking a common sense approach to new situations
19. To work as part of a team cooperating with the Advocacy Development Worker in particular and covering for other staff during absences from work as requested by the Director.
20. The post holder may be asked to re-organise their work in order to help GATE respond to changes in type or extent of identified need. This would be done in ways consistent with the purposes of the post and in consultation with the post-holder.
21. To promote a positive image of people from the Gypsy / Traveller communities and adhere to the values of GATE in all activities

Person Specification	Application form/interview (AF/I)
Experience	
Two years experience of working directly with community members in the voluntary, statutory or health sectors.	AF
Experience of addressing social inequalities	AF/I
Experience of monitoring, evaluation and report writing	AF
Experience of project development	AF
Experience of working with local communities to identify need	AF
Experience of partnership working across sectors	AF
Experience of fund raising	AF
Knowledge and understanding	AF/I
Issues affecting members of excluded community groups	AF/I
Awareness of health related agencies and services available in Leeds	AF
Understanding of multi-faceted discrimination	AF/I
Qualifications or training	
NVQ level 4 or equivalent in relevant professional area (eg, social work, community development etc) or the ability to demonstrate through practical experience the capacity to work at that level	AF
Skills and Abilities	
Ability to liaise and negotiate with community groups, health service managers and other service providers	AF/I
Ability to think and act strategically	AF/I
Ability to effectively present information in a variety of medium and to a range of different groups of people	I

Good IT skills	AF
Good level of literacy and numeracy	AF
Ability to relate positively to community members in a sensitive and culturally appropriate manner	I
Good verbal, listening and communication skills	I
Good administrative skills	AF
Ability to travel throughout target area as required	AF
Attitudes	
Commitment to confidentiality, equal opportunities and challenging discrimination	AF/I
Non-judgemental and person centred	AF/I
Commitment to involvement and inclusion of clients	AF/I
Commitment to team work and supervision process	AF
Commitment to personal and professional development	AF
Willingness and ability to work in a flexible manner including out of hours where necessary	AF

Registration

It is recommended that practices have a policy of registering Gypsies and Travellers as permanent residents where ever possible. In developing their policies, the following points may be helpful:

- When a person registers permanently with a new GP they are automatically deregistered from their old GP (this is a legal requirement) and their medical record is put into transit (the summary care record or universal GP to GP record transfer being still some way ahead).
- Not all Gypsies and Travellers follow a nomadic lifestyle; many have a permanent address and may choose to travel for part of the year – if at all. But for those who do move on frequently and continuously there is a practical point to consider in relation to permanent GP registration: this is that there is a possibility that their health record will never catch up with them - which in turn could make it harder for a new GP to talk to the old GP about their health history.

De-registration

There are circumstances where the PCT must deregister any patient who has left the area, including:

- Paragraph 26 of Schedule 6 to the GMS Regulations, which refers to registered patients who are being treated elsewhere as Temporary Residents for more than 13 weeks.
- Any patient who intends to be away from the UK for more than three months (or is away for more than three months) has to be removed.